

SEDAP

A PROGRAM FOR RESEARCH ON

SOCIAL AND ECONOMIC DIMENSIONS OF AN AGING POPULATION

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Influencing the Experience of Chronic Disease:
A Focus on Individuals with Severe Arthritis**

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April 2001

The Program for Research on Social and Economic Dimensions of an Aging Population (SEDAP) is an interdisciplinary research program centred at McMaster University with participants at the University of British Columbia, Queen's University, Université de Montréal, and the University of Toronto. It has support from the Social Sciences and Humanities Research Council of Canada under the Major Collaborative Research Initiatives Program, and further support from Statistics Canada, the Canadian Institute for Health Information, and participating universities. The SEDAP Research Paper series provides a vehicle for distributing the results of studies undertaken by those associated with the program. Authors take full responsibility for all expressions of opinion.

Social-psychological and Structural Factors Influencing the Experience of Chronic Disease: A Focus on Individuals with Severe Arthritis

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Abstract

In-depth personal interviews were conducted with 29 men and women with severe arthritis of the hip or knee. All respondents had been identified by medical experts as having demonstrable need for total joint arthroplasty, but in assessment in another study, had stated an unwillingness to consider the procedure. In interviews, we explored 1) current self reported health status and co-morbidities; 2) features and functions of the informal and formal support network; and 3) general orientations to aging, illness and independence, to examine the influence of these on participants' strategies for coping with severe arthritis and their views of treatment options. We present a multi-level model of the social-interactional and social-structural features of lives in which the experience of arthritis and responses to it are contextualized. Interviews reveal a complex set of experiences and responses: participants frequently reject the medicalization of their arthritis; they normalize the experience of functional decline (ie: they modify expectations to fit their capacity), or define it as age normative; they draw on a broad set of previous experiences from the lay health care system as well as from the formal medical care system to define an appropriate strategy of coping for the "here and now". The discussion focuses on the distinction between objectively assessed *disease* and subjectively experienced illness, and the implications of this distinction for medical practice.

Keywords: illness experience, lay perspectives, social context, decision-making, chronic illness, arthritis

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Introduction

Arthritis is a common and disabling condition, whose incidence is growing relative to an aging population. Current evidence is that arthritis is under-treated (Hawker, et al., 2000; Hawker, et al., 2001). These investigators document a wide gap between potential need as defined from a medical and surgical point of view and patient willingness to consider surgical intervention, highlighting two factors that governing health care utilization patterns: the prevalence of illness and the preferences of patients (Hawker, et al., 2001).

The relevance of understanding the discrepancy between medically assessed *need* and patient preference for a treatment is of growing importance given the aging of the population in Western countries, and the increasing prevalence of chronic disease in those populations. Arthritis, for example, affects almost 30% of the population aged 65+. It is a leading cause of permanent incapacity, and results in extensive utilization of health care resources. It is also a primary factor leading to institutionalization of elderly individuals, particularly unattached elderly women (Hawker, et al., 2000).

Preferences for health care services by patients may vary according to both medical and non-medical factors. For example, the nature of arthritis determines that afflicted individuals usually age with the disease. This long-term experience takes place within a changing social context so that the effects of the disease are re-interpreted as the context changes. The illness may take on a different meaning for the individual who, with time, has increasing experience managing the disease. The meaning of symptoms as well as decision-making with regard to symptom management may be influenced by previous successes or failures in coping, including the successes and failures of medical interventions.

The distinction between the concepts of *disease*--representing physiological dysfunction at the level of cells, organs or bodily systems, and *illness*--the subjective state of wellness or ill-health (Susser, 1973), is highly relevant here. While medical interventions are focused on disease, laypersons' perceptions of the significance of medical diagnoses and directives are mediated by the subjective evaluations of physical symptoms--which are, in turn, influenced by the individual's social environment. The purpose of this paper is to understand and illustrate the lay interpretations of the illness of arthritis, and the factors that influence those interpretations, to help clinicians better treat patients. In this paper, lay-interpretations of [and responses to] the illness of arthritis are examined, and a broad theoretical model of the factors that influence those interpretations is presented.

Methods

In contrast to quantitative methods of data collection which decontextualize subjects' experiences of a phenomenon by containing or bounding responses to inquiry, for "meaning seeking" research such as this, it is appropriate to integrate the context of the disease in order to understand its course and outcome (Dill et al., 1995; Pearlin, 1992). We undertook in-depth, face-to-face interviews with the study sample. The interview was focused around the general question, "how do aging individuals' perceptions and experiences of arthritis influence health care decision-making and management of the illness?" The research question is oriented toward action and process around respondents' ongoing assessments of the relationship between their disease condition and environment, and subsequent responses to it.

Sampling Methods and Sample Characteristics

The study is based on a convenience sample of individuals who have arthritis, who were selected for

this study based on clear inclusion criteria: following a three-stage assessment in a large epidemiological survey, they have reported and were objectively assessed as having *severe arthritis*; they were assessed as appropriate candidates for total joint arthroplasty (tjr); and they rejected the tjr option after being given detailed information about the risks and benefits of joint replacement surgery (for details see Hawker, et al., 2000; 2001).

A total of 29 individuals were recruited for the study: 16 from a rural/small town area of the province of Ontario, and 13 from a metropolitan area. The sample included a diverse age distribution, with respondent ages ranging from 59 to 86. Respondents in this study included 20 females and 9 males, 17 were married, 8 were widowed, 2 were divorced, one was never married; one did not indicate their marital status. The sample size is appropriate for qualitative research, where saturation of substantive themes in in-depth interviews is quickly reached in relatively homogeneous populations (Glaser and Strauss, 1967).

Data Analysis

Interviews were tape recorded and transcribed verbatim. Transcripts were subjected to inductive content analysis (Berg, 1995; Holstein and Gubrium, 1994; Strauss and Corbin, 1994; Glaser and Strauss, 1967). This involves multiple readings of the text to a) develop an overall sense of the major issues being raised; b) generate a complete list of themes and issues--this phase is complete when the themes have become “saturated”, that is, when the codes have become repetitious; c) analyze of this open coding scheme to develop a systematic coding frame of codable themes. These codable themes will reflect correspondences, differences and patterns which appear in the data; d) additional readings to apply coded themes and assess theoretical meaning. Analysis of the transcripts, following

this pattern of iterative review of themes moves from description to explanation, from the concrete to the more abstract (Glaser and Strauss, 1967).

Results

Analysis of transcripts resulted in the general model outlined in Figure 1. The model integrates micro-, meso- and macro-level processes that contextualize the experience of arthritis and influence decision making regarding its management. These levels and processes are illustrated and discussed more fully below. The model also denotes temporal dimensions that depict the illness experiences across an individual's life course, potentially from birth to the present; an individual's knowledge of significant others' experiences of illness, including individuals from previous generations; and projected expectations for the future for which the individual may or may not be currently preparing. These temporal dimensions are revealed in the discussion below.

...Figure 1 about here...

The Body. The first component of the model is identified as “the body”, and represents the micro-level, intra-individual “embodied” experience. The bodily experience of arthritis and its history were described in detail by participants to the study and generally confirmed in all cases the existence of severe disease, as determined by functional limitations and pain. Self-reported co-morbidities were also described by participants, and the perceived seriousness of both current or previous co-morbid disease conditions complicated respondents' evaluations of arthritis and perceived options for its treatment.

In all, 26 of 29 participants reported medical complications in addition to arthritis. These must be assessed in order to understand the context and process of health care decision-making with respect to arthritis¹. For example, respondents prioritized co-morbid conditions, so that in almost

every case, the medical management of arthritis symptoms was foregone or avoided. Respondents used a strategy of self monitoring of pain and anti-inflammatory medications for arthritis, primarily through well-tested trial and error strategies, but also through what could be called the “do or die” strategy, where they describe avoidance of all medications until they’ve reached their limit in coping. These tactics were motivated by patients’ views that other conditions were more serious, and by respondents’ astute knowledge of (ie: experience of) negative side effects of various drug combinations they have been prescribed.

Thus, even simple discussions around self reported health status and history reveal that the “embodied condition” is not objective, but interpreted. The meaning, significance, and response to the bodily state at a single point of time is determined by an interpretative process whereby the individual evaluates his or her current state and options for treatment vis-a-vis previous and current conditions, interventions and outcomes.

The Self. The second component of model is labelled “the self”. The study of the self is concerned with the implications of the human capacity to reflect upon one’s own physical, social and psychological state (Mead, 1964). The concept of identity refers to attributes, actions and appraisals of the self (Charmaz, 1987: 284). Personal identity is a general term reflecting a person’s sense of a relationship to others and recognizing past relationships and roles, so identities influence and shape the evolving self (Charmaz, 1987; Yoshida, 1993). The self is a social-psychological concept, because the boundaries and expectations of the self are learned by an individual through social interaction with others.

In focusing on individuals’ evaluations and interpretations of illness (the subjective experience) rather than focusing on the disease, or objective state, much can be learned about an

individual's expectations for themselves--their identity concepts and identity projects--that shape subsequent actions or responses to chronic illness. Much of the content of the qualitative interviews with individuals with chronic arthritis involved evaluations and interpretations of the illness, set against a backdrop of personal expectations and philosophies of the self. These interpretations are key to understanding the "logic" of individuals' decision-making about health care interventions for their condition of arthritis.

Four general perspectives on arthritis as it relates to patients' self concepts, were revealed in the analysis of the transcripts: arthritis as non-problematic aspect of an integrated identity; arthritis as age-normative (integrated into the self concept); arthritis as an identity challenge; and arthritis as an invasive feature of a "spoiled" identity (Goffman), that overwhelms one's former intact self.

First, in several cases, arthritis was an inconvenience, but in no sense represented a challenge to one's identity or their sense of self; of who they are. Often respondents simply stated that you just have to live with it. For example, this 65 year old woman stated:

"As I say, I've never really pushed the fact that I've got the arthritis because it was just basic well you've got it so you live with it. You know, it's the way we've thought about it, that you've got it, there's not a lot can be done about it, so you basically live with it."

Second, as has been found with other research on chronic illness (Charles and Walters, 1998), arthritis, and illness in general, was often interpreted as a normal and expected aspect of aging. The following discussion with a 79 year old woman illustrates this point: (other eg?)

R: You know, I'm going to be 80 in August so I can be thankful I had this much mileage.

I: Do you have any other illnesses or health problems besides the arthritis?

R: (Chuckles) At this age you have all kinds of problems.

I: I know. But some people have more than others.

R: *Oh I have, ah, little bit of asthma, and a little bit of a heart--my muscles around my heart congest like, you know.*

This woman's comments illustrate that while she recognizes her disease conditions, they are integral to her sense of self at her current stage of life.

Third, for chronic illnesses whose impact became significant only in later life, the effects of the condition may come to be interpreted as an entity separate from the self. The condition thus becomes a challenge or an identity project-- which may involve the integration of the embodied condition into the self concept, or the rejection or denial of the embodied effects in order to protect the current self concept. The successful management and negotiation of the condition by the "independent" self may then reflect a strength of character that is valued by the individual.

The notion of the condition being separate from the self is illustrated in the following excerpt:

"What seems to be the problem is if you're feeling well, you think--you forget you've got this, you know. Its like you go out and you overdo and then you come home and, you know, its very painful."

In attempting to carry out her normal activities, this woman is reigned in by the arthritis which imposes itself upon her. In another example, a 71 year old man, after describing his pain and incapacity from arthritis as well as serious co-morbid conditions including degenerated disks and diabetes, states:

"Actually, I feel very good...if it wasn't for all this..this pain stuff, ah, I wouldn't be too bad";

Later went on to remark:

"Ahm, well my own health has been good, you know, ah, except for this nonsense...my back and everything but, ah, other than that I'm--I guess I'm a fairly healthy person, you know."

Here, the gentleman is expressing the separation of his *self* from the chronic conditions that have

attached themselves to him.

Additionally, taking the management of symptoms as a head-on challenge is illustrated in the following excerpts, with the independent resolution of daily activities a victory for the challenged. In the following case, a significantly disabled woman in her 60s, described the challenge of keeping up her own house, but also her daughter's, for whom she babysits on a full time basis:

R: What I've been doing since last, ahm, October, I've been babysitting my two grandchildren. One was 5 at that time, the other one was two. And ahm, but I did it.

I: Good for you.

R: Okay? So I had to keep up this place and try to keep up theirs too, eh?

I: Ooh, this is...a lot of work.

R: Yeah. So there's a lot of pushing there (chuckles). Which, well I'm...kind of pleased that I was able to do it at first, it was very hard really, but you know, I pushed and pushed.

In another example, a man responded to the interviewer's question about whether or not he would make use of formal home care services:

"...yeah, but I don't need their help. I can do everything. But it hurts but I do it. But I stand to wash the dishes; I got to go and sit down after a while because of this leg here. And this one--this foot here goes numb from the side...

The conversation with the interviewer continued later:

R: I still look after myself, I keep going, I don't give in to it.

I: Yeah. Well, you're living like a hero, like somebody who is never going to be sick.

R: Well, I never--I've never had a disease in my life.

In the above comment, the respondent was referring to acute diseases of childhood; he clearly did not include his experience of arthritis as a "disease", nor his impairments as disability. This man's sense of self is being safeguarded by his attitude of self sufficiency. In fact, there were numerous examples

of individuals' perspectives of and behaviour related to the management of their illness(es) reflecting a general personal moral philosophy on dealing with life.

For some, the personal philosophy of stoic independence often led to the rejection of formal assistance, including, as mentioned previously, the use of medications. For example, the comment of one 60 year old woman reflected strong wish to avoid "giving in" to the pain she experienced daily. She explained to the interviewer:

I: Do you need pills for pain? Or pain control?

R: Ahm, no I just take prednisone. Now I am...occasionally I will break down and take a tylenol.

In another interview, a similar conversation was evident:

I: Yeah. So how do you control pain?

R: How do I control (chuckles). I pray about it (laughs) and I say 'Lord, help me'. It does, it does help (chuckles). And ah, if I really get really painful or if I haven't slept for, you know, couple nights, and I realize oh, I'm tired, I need something, I'll take some of the tylenol.

In another example, the options for gaining information about alternative ways of dealing with the debilitating pain of her arthritis is greatly limited for this 77 year old widow because of her stoicism, and extremely strong views about privacy, self sufficiency and household standards:

I: Yeah. Okay. Okay, so you didn't (take) any pills. Did he [doctor] recommend any exercise or something?

R: Well, no, he didn't. But he knows I'm very active; I try to do everything. Mind you, it's slow and it's painful, but I try.

I: Okay. So do you exercise now?

R: Oh yes. I swept this morning the steps and the sidewalk, and you see my pile of things there, and that's a hard job for me.

I: I understand. This is quite brave too.

R: Yes, I do; I don't sit and mope.

Part of the interview involved asking respondents about the availability of their social network for support and assistance. In this context, the above interview continued:

I: So do you talk about, you know, aches and pains?

R: Never to anyone.

I: Never to anyone.

R: If they ask me how I am I have one answer, 'fine'.

I: Okay.

R: I feel other people have problems.

But I just say fine.

Finally, other examples illustrate the difficulty when one's identity is overwhelmed by the effects of the physical condition, and arthritis (or other illness) becomes a pervasive identity feature. This 71 year old woman is completely dependent on her husband for almost all activities in the home and out. The following conversation occurred:

R: He has to cut my food; he has to walk me to the washroom, back out here again; it's so horrible.

I: it's frustrating. I understand.

R: Oh, it is! And especially someone who was always used to doing for myself. You know, I've been working since I was twelve; and to have to depend on somebody so totally, it's really horrible. I'd like to be able to get up and kick my heels up and you know, just do all the things other people do.

This woman's former (and preferred) identity is unrecognizable in the current context of her life; she has multiple and serious co-morbidities and has been left physically and psychologically unable to rise to the challenge of her physical limitations. Throughout her interview, this woman made frequent reference to her past self and roles...lamenting the losses she has incurred.

Illustrations such as these suggest that in order to understand the *meaning* of chronic illness for an individual (and hence their responses to it), it is important to understand the extent to which it challenges an individual's sense of self; and the extent to which the previous self-concept as well as the normal routines of that individual are disrupted by the condition. These illustrations also demonstrate that evaluations of arthritis are based on much more than the physical status of the disease, or on co-morbidities. In the data derived from the current study, broad life experiences, beliefs and customs, and the everyday practices and activities of the respondent influence orientations to arthritis and responses to it.

The "Extended Self". The third component of the model illustrates the ways in which micro-level social interactional experiences and organization determine both the meaning of illness for an individual, and responses to it. The "extended self" component represents the notion that for some respondents, the meaning of arthritis and responses to it are based on the marital or intimate couple's capacity to contain and respond to physical challenges. The data suggest that respondents may conceptualize functional declines not in terms of the individual's functional status, but the married couple's capacity to function interdependently. The couple's capacity, then, determines an individual's health care decision-making. This notion of *marital synchrony* is illustrated in the following excerpt:

I: *Oh. Well, how do you handle the housework?*

R: *We do it between the two of us. If we don't do it today it gets done tomorrow or some other day. Don't worry too much about it.*

I: *Who does the groceries, or how do you do it?*

R: *Both of us. We go--we go with the Wheel-Trans, (coughs) that way she doesn't have to do much walking and I have this wheelchair anyway.*

Later, in discussing his intention to avoid joint replacement surgery, this man again refers to the availability of his spouse to support his continued independence:

well...if they..if there've been two people and one dies, the other one gives up altogether. But we got each other and that there keeps us going. I think that's what helps a lot really...

However, the quality of the marriage and level of dependence may very much matter here. Returning to the interview of a woman quoted earlier, the following excerpt illustrates how powerless she feels in the face of her increasing dependence on her husband:

R: I got everything wrong with me and I feel so useless.

I: Oh! This is sad.

R: You know, you can't help it but...feel useless when you've worked all you life and done everything for yourself, and then you find that you just can't do anything. You know, I mean, it's really embarrassing when you have to--he has to help me to walk, he has to help me up the stairs. If I'm going, ah, I'll walk--I'll go the wrong way. You know, it's so, oh, it's so bad. And people don't realize...

This interview revealed a complex relationship between the couple—one where both support and conflict; affection and discord was evident.

Another woman, married 40 yrs and with serious disability but a tremendous will to maintain all her former roles, made this comment about her relationship with her husband:

I: So, yes, I was going to ask you about your husband. Do you talk with him about...?

R: Not much. He's....he's not the type, ahm, he doesn't like to hear people, he puts it, complain, okay. So there's not much there to, you know, to talk it over with.

This woman had severe pain and dysfunction, but stated that she alone continued to maintain her household and personal care, with no expectation that her spouse would assist.

These examples suggest that the health care decisions of an individual may be influenced by the level of functional and emotional synchrony in the marital or intimate relationship where the

everyday experiences of the illness takes place. This finding substantiates those of numerous community health surveys examining the relationship between mortality and social networks which indicate the importance of the single confidante or a single close and intimate tie, but these data suggest that the presence of a marital partner doesn't *necessarily* imply the relationship is functionally synchronous. This latter point is parallel to one made by Hamberg et al. (1997) in regard to their study examining the impact of the marital relationship on the rehabilitation process of women with long-term musculoskeletal disorders.

Formal and Informal Resources: The fourth component of the general model is focused on the formal and informal resources that assist the individual in maintaining roles and accommodating their illness with limited or no medical intervention.

With respect to *informal resources*, there is some overlap between the role of the spouse and that of other members of the informal network (ie the family, extended kinship and friendship networks) who assist an individual to accommodate physical limitations, and thus influence the extent to which the individual is able to maintain an intact sense of self. Generally, the impact of the informal support network on influencing an individual's health care decision-making is demonstrated in four ways in the current study:

- 1) it provides instrumental support that minimizes the extent of dysfunction experienced by the individual including assistance with ADL's and IADL's; and
- 2) it provides perspectives and information to the respondent on appropriate strategies of care than may or may not include medical care;
- 3) it provides affective or emotional support, so that, for example, an individual whose disability leaves them home-bound remains socially connected in meaningful personal relationships;

and

4) it serves to establish and reinforce a micro-culture which defines what is an appropriate response to illness, in general.

The first three aspects of assistance parallel three types of social support discussed in the broader literature in this area: instrumental support, informational support, and emotional or affective support. A most interesting and unexpected finding in the assessment of how the informal social network influences the perspectives and behaviour of respondents is the extent to which family and community values and norms of behaviour are transmitted across generations to provide guidance for aging and illness, the fourth aspect of assistance noted above.

The following excerpts indicate how [current, near or distant] relationships with family members and significant others provide role models for behaviour, and help respondents define their philosophies and standards of living. The following excerpt is from an interview with a 62 year old woman who had maintained a very strong, involved relationship with her parents (now deceased) across her adult life. Of her mother, she stated:

R: She was eighty...eighty-one or eighty-two when she had that and that was her first major surgery....she was a very, very strong woman. And she never felt pain. Which is extremely bad. That's worse than somebody who is always in pain; to feel no pain is worse than ever...

This woman went on:

R: My mother had arthritis too.

I: Okay.

R: But she wouldn't let it get her down either. My mother was the most marvelous knitter and crocheter. And she could make pastry! Oh, how I wish I could make pastry. She

made the most beautiful pastry, but her hands were twisted with arthritis. These two fingers were twisted really badly.

I: Badly, heah, um-hm.

R: And these two. And ah, she ahm, but she still continued until the last two years of her life.

Additionally, this woman noted the impact of the loss of her husband to cancer (she was widowed only 6 months prior to her interview), and perhaps more importantly, the loss of a child to leukemia, on her own evaluations and responses to her personal health status:

R: I lost my first son to leukemia thirty-four--thirty-five years ago last March. He'd be forty-two now. He was quite a man. He was seven years old when he died, but my god, that child went through more agony in one year than most human beings go through in their lifetime. That's why I don't give in. (Emphasis added)

I: Yeah. I understand very well, yeah.

R: That's why, when we got cancer I...I could handle it. A lot of people wouldn't be able to, but I could. (Emphasis added)

Another respondent, describing his family history of arthritis, recalled his mother's coping--which was reflected in his attitude toward dealing with his own arthritis:

I: Okay. So do you have in the family a history of arthritis?

R: Oh yeah. Mum was crippled up with arthritis. She was in a wheelchair. She had it in her knees terrible...she had cancer too....that's why the ramp and that's there; she died what was it...two years ago?....she tried her best to...till the last two years she wouldn't --she went, she crawled upstairs.

This man's mother died at age 97, perhaps accounting for his resilience and resistance to the medicalization of his aging body, at age 81.

The above illustration indicates how the extended generations within a family may define for

an individual the “normal” and expected life span, and norms for coping with symptoms. In the following example, the woman’s response to her arthritis condition is circumscribed by her thoughts about the years remaining in her life. In a conversation about the potential benefits of choosing to operate earlier in the progression of the disease rather than later, the interviewer probed:

I: *...some people think well, I will wait until I have done everything else and this will be the last resort thing. And some people think the other way around saying, well in ten years I may be too old and it may be too difficult for me to recover from such an operation, so I better do it a little earlier, a little before I become too dependent. What do you think?*

R: *I don’t know.*

I: *Which philosophy looks to you more...makes more sense?*

R: *I don’t know (chuckles). You think I live another ten years? I don’t know.*

I: *Why not?*

R: *My mother died very young, sixty eight.*

I: *Sixty-eight.*

R: *I’m sixty-five. I don’t know how much I live.*

In another case, a 60 year old woman described how her mother’s response to illness served as an illustration of how *not* to behave:

I: *and...how do you feel...in terms of your feeling of age?you know, people have different feelings.*

R: *I--no, I don’t - I don’t feel old. Even when I think about retiring [which she plans to do in a few months’ time] I think to myself, ‘you know, L., you could work another few years’. I mean, why not? But I really think it’s time that I did, and I...no, I don’t feel old. I really don’t....and I’ve always tried to be that way ‘cause my mother was the opposite; she enjoyed her sickness, anything, if she had an ache or pain, and I made up*

my mind I would never be like my mother, that way. Because people don't like that; and she lost friends because she would just talk about her problems, and people don't like that. So I made up my mind I'd never do that (Laughs).

I: Okay. That is...that is a good point. When did you think about this?

R: Oh, she used to even, you know, when my mother - she died in '78. I think - she was like that for a number of years, maybe ten or fifteen. She was like that after my brother died. My brother died of cancer and he was only thirty-three. And after that she just was a different person and she just....just dwelled on her, you know, she had high blood pressure and she had this and that and the other and...and she just dwelled on it. People don't like that. So I try not to bring up, even at work, my one boss, he was asking me, "oh, how are you today, L.? How are things today?" I finally said, "A, I'm fine. Just don't bother about me. I'm here", I said, "you see me limp, I'm limping today. Just don't bother me".

Finally, another example illustrates how respondents' experiences within their families socialized them to perceive and manage their own illness, including the management of uncertainty.

This woman was describing for the interviewer a typical day's routine:

R: Ah, well, I get up, I go out for a walk every morning I do that always. And then I come back to what I have to do and, ah, I usually do a bit of, ah, of ah, I usually have a rest after lunch, which is noon, ...and then I go and usually do a bit of work, and ah, that's it for the day. But an, I mean my mother had this too, of course, and I mean, she got to the point where she couldn't prepare her meals. I mean she couldn't do anything really. And ah, she just seemed to sink right into that. She didn't want to do anything, you know, and ah, so I mean, you know, you think well, is there any way to avoid this, or am I---is this the way I'm going to end up like that too?

I: Yeah.

R: You know, who knows....from my own experience, the worse thing I can do is sit; sit

around. You know, I never do that because, ah, I mean, it's just now I can just feel, you know...you have to keep moving or I can only speak for myself but I have to keep on moving.

Referring again to her mother, this individual states:

R: well, I know that she took a lot of medi--she took, an enormous amount of medication which created other side problems, and I mean actually I can remember going to the hospital and I almost sued them because she was so medicated she... she didn't know what she was doing, actually. It was over-medicated, you know.

I: Over-sedated, yeah.

R: Yeah! And ah, I mean that's another thing. I don't want to fall into that, you know.

The frequency of respondents' references to significant other's experiences and response to arthritis (and illness in general) was striking in this data. The concept of "availability bias" (Tversky and Kahneman, 1974) from cognitive psychology is relevant here for describing how individuals' perceptions of their own prognosis is based on their knowledge of a highly selective reference group of others who they perceive to have had similar experiences. This finding is similar to that Charles, et al. (1998), who describe how assessments of survival and options for breast cancer treatment is based on subjects' personal knowledge of an acquaintance who had had the disease. More broadly, the data in the current study demonstrate the utility of *social learning theory* (Bandura, 1969; 1977) for describing how significant others' current behaviours/attitudes as well as recollections of significant other's past behaviours serve as *scripts for their own actions*. The data also suggest how behavioural change occurs, as when individuals' interpretations of (an)others' response(s) leads to modifications in the prescribed behaviour or response. In other words, the individual learns vicariously, in the context of their informal social world, possibilities for actions; these are passed

down from one generation to the next--with varying degrees of modification.

Individuals' interpretations of arthritis and options for its treatment, while strongly influenced by the informal network, are simultaneously influenced by knowledge of and access to various *formal resources*, such as medical care, alternative health care (from chiropractic to acupuncture and herbology), and formal housing and related support services. The data demonstrate that most respondents in this study had extensive medical care experience, but *the medical care strategy at the point of time of interviews is assessed within a broader context of alternatives, and against the perceived effectiveness of previous medical and hospital experiences related to the entire history of their arthritis experience*. As noted above, respondents' evaluations of the legitimacy of medical care for arthritis are influenced by their knowledge of others' experiences of hospital and medical care, and other's, particularly family members' philosophies on self sufficiency, entitlement to public services, orientation to alternative methods of care, etc.

Further, the appeal and legitimacy of various types of medical interventions for arthritis are also stratified along a continuum of alternatives. In general, occasional medical check-ups are sufficient, although some respondents in this study had abandoned any medical strategy for arthritis, except the selective use of prescription or non-prescription analgesics. Most respondents indicated they would only "succumb" to invasive medical interventions after other options were tried, and, often, only as a last resort.

Other formal care "support resources" were preferred by some. For individuals who had the ability to pay, purchasing services, or hiring help such as a health care aid in the home, allowed them to maintain a normal life in the home. Some resisted the decision to use publicly provided social or health care services; these were often seen as the entitlement of only "those who need it", or were

rejected because “ someone might need it more”. It was clear that the entitlement to health care provided in doctors’ offices or in hospitals was more legitimate than that provided in the community, perhaps reflecting this (older) generation’s experience with the medical and hospital care system in Ontario that had been available during their adult lives.

The perspective of arthritis as non-life threatening and age-normative appears to influence decisions for arthritis management. For example, in contrast to a study of patients’ views of options for breast cancer treatment that “doing nothing is no choice: ”, (Charles, et al. 1998), in the current study, individuals with arthritis perceive “doing nothing” in the medical sense as a viable and preferred option until circumstances force one to turn to increasingly invasive methods of management. Repeatedly, the tjr option was expressed in this light, as an option of last resort.

In summary, in combination, informal and formal resources structure [establish as possible] a set of alternative courses of action, and in doing so, they both create new or reinforce existing belief and knowledge systems that determine individuals’ strategies for disease management.

Generational Culture. The final component of the model, “generational culture”, refers to the values and norms of a particular generational group that guide or influence the meaning attached to the self/body dilemma imposed chronic illness². The notion of generational culture denotes static or distinct within-group norms of behaviour, rather than the transmission of those norms of behaviour through cross-generational (intra-familial) socialization, as previously discussed. For example, in the following case, a 77 year old respondent makes explicit reference to the specific cultural rules that dictate her perspective on, and behaviour related to the management of arthritis, and she defines this perspective as generationally distinct:

I: Have you thought of what kind of --what services you may need in this area and, enquiries

into what is available?

R: I can't answer that. I don't know.

I: I mean, there are all sorts of opportunities and I guess you haven't needed them...

R: That's right.

I: ...which is better. It's better if you don't need them.

R: Yes! Yeah, I would probably try to find...but you know, I come from the old school.

When you're this old, you grew up with nothing and you learn to do with nothing, and you learn to look after yourself, you know, as long as you could anyway, so I guess that's what we do. We just...I don't know...I'm only going from one daughter-in-law, the slightest thing....she goes and has it fixed, eh. And I'm not saying it's not right, but she's sure using the medical business and she's good and healthy and all that now, maybe that's good. She had an operation on her feet; she had a bunion removed from one foot and then a year later she had one done on the other foot. She had a quite prominent one there. Inherited, she said. And she didn't hesitate about going and having it done. Now me, I woulda lived with it, you know. So it's just--it's better her way. She's taking advantage of what's available.

I: I see. I guess that's what you are...I mean...

R: (overlapping) that's what you are, yes, yes, alright. And I don't think that will change; as long as we can look after ourselves, we will.

Without longitudinal data examining aging cohorts, it is difficult to state definitely whether the values such as those expressed by the above respondent are generationally specific, but this comment suggests that for some, it may be generational culture that determines both attitudes toward an illness, and strategies for managing it. The values such as independence, self-sufficiency and stoicism in the face of adversity are particularly prominent in the data. These same attributes have been noted as characteristic of the elderly in another study that examining age differences in

perspectives on health and illness (Charles and Walters, 1998).

In summary, while it is difficult to ascertain in the current study whether these findings are evidence of an age-developmental process or of a generation's cultural ideology, the data suggest that the capacity to suffer functional loss and pain may be governed by social rules that are generationally specific (ie: younger arthritis patients may be less tolerant of functional decline and more willing to undergo invasive surgery as a means to cope with severe arthritis). It will be worth examining further with the aging baby boom population-- which may have very different opinions on the legitimacy of medical technology, a greater sense of entitlement to public services, as well as a greater expectations for "quick fixes" such as total joint replacement. A clear finding in this study is the skepticism of these elderly respondents regarding surgery: despite the clear information provided to them about the limited risks involved in the tjr procedure, and despite the fact that in many cases, respondents knew of (an)other(s) who had undergone successful joint replacement, they expressed an unwillingness to subject themselves to joint surgery, at least at the point of the interview. Other studies have noted that a generational effect may help account for the health care decision-making of the elderly, (Haug et al. 1997: 550; Karlson et al., 1997:. 529) and these studies have noted that longitudinal data are required to systematically examine such an effect.

Discussion

This research demonstrates a range of social factors that mediate the effects of disease on subsequent health care decision-making, and illustrates that there is a considerable level of plasticity in perspectives on arthritis-as-illness, and in the maintenance of function in the face of severe disease among a sample of elderly participants. The "embodied condition", the identity projects undertaken to sustain a sense of self; the informal and formal network available to assist in those projects or to

define them, all influence the process of disease outcomes that emerge over time.

Five general statements summarize the components of the model presented in Figure 1. *First, the “embodied condition” of arthritis is more than an objective state; it is a subjective experience whose meaning and process are interpreted within a broader context of disease, illness and health.*

Second, the widely differing interpretations of study participants with arthritis and of medical experts who defined these individuals as in need of tjr, reflect the much broader realm of experience drawn on by patients to assess the meaning of symptoms of arthritis such as functional decline and pain. For patients who were medically assessed as having severe disease, four general perspectives on arthritis emerged from the analysis of transcripts: arthritis as non-problematic; arthritis as age-normative; arthritis as an identity challenge; and arthritis as a pervasive identity feature. These general perspectives dictate the responses to symptoms.

The importance of maintaining a coherent sense of self through “identity work” (Adams, et al., 1997; Mathieson and Stam, 1995; Crawford, 1994) emerged from interviews. Respondents indicated various strategies for maintaining their sense of self in spite of the physical disease. Two active strategies for maintaining the self involved either denial of the conditions or their effects, or the integration of the effects of arthritis (physical limitations, management of pain on a daily basis) into the identity project, while the perceived/preferred self was passively supported when illness symptoms were described as non-problematic and age-normative.

The importance of the maintenance of self reinforces discussions about identity, stigma, and chronic illness. As an illness, arthritis is less stigmatizing than conditions such as AIDS (Crawford, 1994) or asthma (Adams et al., 1997), but established folklore on arthritis as an expected aspect of elderhood (Charles and Walters, 1998) may lead to stigma when the afflicted are seen as rejecting

that passage by medicalizing their bodily experience. When medical interventions challenge cultural or generational values--in these data, values such as independence and stoicism,-- the effect may be the same: where the illness label marks the incumbent as “other” in a pejorative slant.

Third, the individual’s sense of self is sustained by the nature and structure of available informal and formal resources, and the negotiation of their use by the individual. The data suggest that respondents may conceptualize functional declines in terms of their most intimate relationships, so that it may not be the individual’s functional capacity, but the married couple’s capacity to function interdependently that determines an individual’s health care decision-making. Additionally, informal ties to others may result in instrumental, informational, or emotional supports that assist the individual in the task of daily living. Formal resources are drawn on simultaneously by an individual based on the perceived legitimacy of resources such as medical and other care alternatives. The informal and formal resources structure [establish as possible] a set of alternative courses of action, and in doing so, they can create new or reinforce existing belief and knowledge systems that determine individuals’ strategies for disease management

These findings of the negotiation of possible courses of action for the management of arthritis support those of Dill et al. (1995) in their study of self-care among older people. These authors conclude that older persons approach, interpret, and treat symptoms within both biomedical and psychosocial frameworks. Further, in their study they conclude that self care responses appear to be learned early in life, reinforced throughout the life cycle, and formed in consultation with professional as well as lay persons; and reflect and project individuals’ own interpretations of the self.

The management of the images of the self, reflected in care strategies, results in distinct

physical, functional and relational outcomes related to disability and the disease condition of arthritis. The distinction between the concepts “impairment” and “disability” is relevant here. Where impairment refers to the physical limitation in normal functioning, disability describes specific limitations in an individual’s performance of socially defined roles and tasks within a particular socio-cultural and physical environment (Jette, 1996). Impairment will lead to disability to the extent that the individual, in the context of a specific informal and formal network, is unable to maintain the status quo in terms of social roles and relationships. The experience of disability is very context-specific.

The experience of disability resulting from arthritis may not only be context-specific, but also historically delimited. An individual’s future decision-making will be determined by the continued response of the individual and his/her social network, as well as by the physical or bodily status. To the extent that the aging body presents increasing functional challenges, and the aging social network is also diminished--with time--in its capacity to provide support of the manner we discuss earlier, the individual will face narrowing options and at a psychological level, will re-interpret previously held views on alternatives to care, and may come to consider strategies for coping previously held at bay. For example, widowhood represents the unequivocal loss of the main source of instrumental support and is a clear marker of the need for alternative methods of management for the individual with physical impairment. It is notable that in the population study, living alone is a strong predictor of willingness to undergo surgery (Hawker et al., 2001).

Fourth, the notions of generational transmission of norms and values which determine everyday attitudes and behaviours of individuals facing the challenge of chronic illness may be antithetical to the notion of generational culture which denotes static or distinct within group norms

of behaviour. Further longitudinally designed research is required to examine whether inter-generational transmission or intra-generational cultural rules for illness behaviour predominate. In the current data, what is most apparent is that elderly respondents are strongly influenced by the experiences and belief systems of previous generations, indicating generational transmission of micro-culture. But they may be estranged from the younger generations' health care belief system and subsequent experiences in the medical care system. This latter point is most aptly illustrated in the excerpt noted above as indicating a distinct generational culture. Furthermore, physicians, who are the gatekeepers to formal health care, may have attitudes about arthritis, in general, and joint replacement surgery, in particular, that vary generationally. That is, older and younger physicians may have different views *and behaviour* when it comes to evaluating treatment options for their patients who have arthritis.

Aside from a re-assessment of the popular discourse that asserts the elderly over-utilize health care services, there are two main clinical and policy implications of this research. First, the findings challenge the narrowness of a biomedical assessment for determining the appropriateness of health service need and/or utilization. These data suggest that clinicians need a broader scope of information about the socio-cultural context of a patient's illness experience in order to recommend a viable treatment course and in order to improve (and understand) compliance. Simply put, there is a need to move the medical assessment beyond the walls of the examination room (see also Hawker et al., 2001).

Second, given that patients may assess medical options for care simultaneously with other options, there is a need to better "market" biomedical interventions. In this study, alternative courses of action in response to arthritis symptoms were frequently chosen by individuals, at great cost to

themselves in terms of pain and functional difficulty, because of the perceived lack of legitimacy of medical practice for these long-term users (elderly) of the health care system. The combination of negative experiences with the medical care system in the past, the lack of knowledge of medical and technical progress (for example, related to improvements in anaesthetic practice, surgical practice, etc); their vicarious knowledge of (a former and much less developed) the medical care system, such as was experienced by their parents, all serve to dampen these patients' enthusiasm for surgical intervention. It is not insignificant that, of the 29 participants included in this study because they are [reluctant] candidates for tjr, only one had a physician who recommended tjr.

Finally, while this study is focused on the experience of arthritis, there are clear parallels to be drawn between both the method and outcome of this research, and other studies focused on health care decision-making, medical compliance, etc. In an aging population, with the increased prevalence of chronic disease in that population, the distinction between *disease* and *illness* must be integrated into studies examining health care decision-making.

Acknowledgements: The original research (G. Hawker, PI) was supported by a grants from the Medical Research Council of Canada, the Arthritis Society of Canada, Physicians Services Foundation, the Canadian Orthopaedic Foundation and the University of Toronto Dean's Fund. Additional support was provided to Peri Ballantyne by the Centre for Research in Women's Health, Sunnybrook and Women's College Health Science Centre/University of Toronto, and the Women's College Hospital Association of Volunteers.

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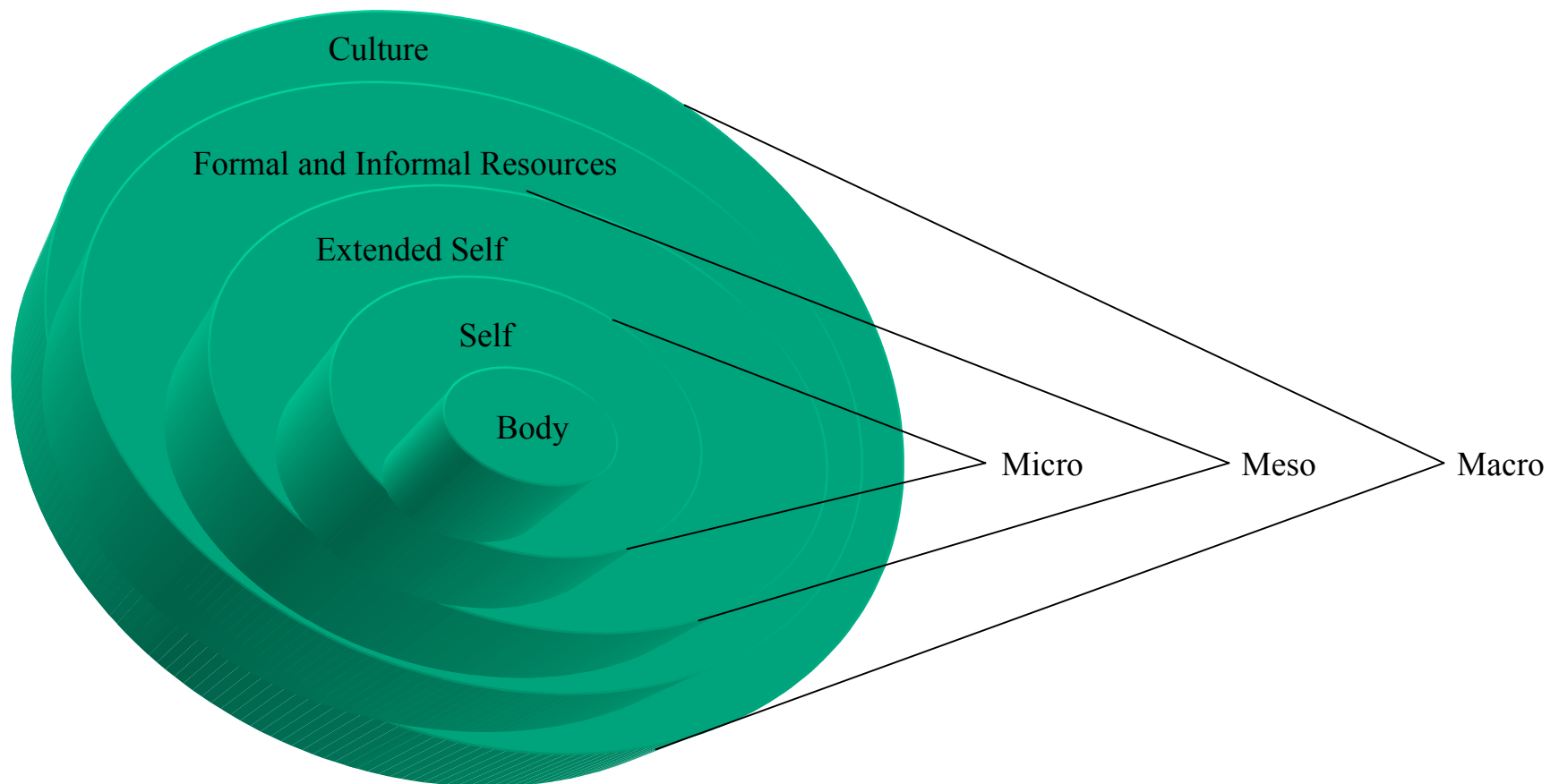
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1. The larger study, which identified the respondents as candidates for tjr, defined a much more conservative list of “absolute contraindications for surgery, including major mental illness, stroke with paralysis or other major neurological disorder”.

**TABLE 1: A GENERAL MODEL OF FACTORS INFLUENCING
THE RESPONSE TO ARTHRITIS**



>>>.....time, personal history, generational history within the patient's family.....>>>

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